

# Combining Community-Based Research and Local Knowledge to Confront Asthma and Subsistence-Fishing Hazards in Greenpoint/Williamsburg, Brooklyn, New York

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Activists in the environmental justice movement are challenging expert-driven scientific research by taking the research process into their own hands and speaking for themselves by defining, analyzing, and prescribing solutions for the environmental health hazards confronting communities of the poor and people of color. I highlight the work of El Puente and The Watchperson Project—two community-based organizations in the Greenpoint/Williamsburg neighborhood in Brooklyn, New York, that have engaged in community-based participatory research (CBPR) to address asthma and risks from subsistence-fish diets. The CBPR process aims to engage community members as equal partners alongside scientists in problem definition, information collection, and data analysis—all geared toward locally relevant action for social change. In the first case I highlight how El Puente has organized residents to conduct a series of asthma health surveys and tapped into local knowledge of the Latino population to understand potential asthma triggers and to devise culturally relevant health interventions. In a second case I follow The Watchperson Project and their work surveying subsistence anglers and note how the community-gathered information contributed key data inputs for the U.S. Environmental Protection Agency Cumulative Exposure Project in the neighborhood. In each case I review the processes each organization used to conduct CBPR, some of their findings, and the local knowledge they gathered, all of which were crucial for understanding and addressing local environmental health issues. I conclude with some observations about the benefits and limits of CBPR for helping scientists and communities pursue environmental justice. *Key words:* asthma, community health, community-based participatory research, cumulative exposure assessment, El Puente, environmental justice, local knowledge, subsistence fishing, The Watchperson Project. *Environ Health Perspect* 110(suppl 2):241–248 (2002).

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The environmental justice movement has consistently challenged researchers and decision makers to acknowledge that scientific expertise is necessary but insufficient to address the multiple and persistent health hazards facing the poor and people of color. The uncertainties surrounding scientific knowledge, such as the adverse human health effects from exposure to multiple hazards, combined with evidence that the poor and people of color continue to bear a disproportionate burden of the effects of environmental exposures and the associated morbidity and mortality (1,2), have led disadvantaged communities to demand a participatory role in defining, analyzing, and prescribing solutions to improve the conditions they face. These communities are demanding to speak for themselves in environmental health research and decision making. In doing so, these communities often emphasize that their experience, contextual and local knowledge should be considered local expertise about the multiple hazards and chronic diseases afflicting their communities. Communities seeking environmental justice are speaking for themselves through a process of community-based participatory research (CBPR). In this participatory research process, community members act as

equal partners with scientists and potentially other researchers in problem definition, information collection, and data analysis—all geared toward locally relevant action for social change (3). I explore how one community, the Greenpoint/Williamsburg (G/W) neighborhood of Brooklyn, New York, has used CBPR to describe and act upon the multiple environmental health issues it is currently confronting. I highlight two community-led research efforts, one targeting asthma and another health risks from subsistence fishing, and suggest how CBPR is helping one urban neighborhood pursue environmental justice.

A key tenet of the environmental justice movement is that communities of color and the poor should have greater participation in research and decision making that affects their lives, partly to ensure that these processes combine science with the social, economic, and political realities confronting disadvantaged populations (4,5). The knowledge community members have about their experience of living with multiple environmental hazards and chronic disease is one of the fundamental assets they can contribute to environmental health research and is often the key resource a community organizes to avoid hazardous environmental

exposures and maintain health (6–8). When communities engage in environmental health research, their primary concern is to help themselves by generating usable or actionable knowledge—information that goes beyond description and analysis and suggests proactive or precautionary intervention strategies (9–11). Environmental justice activists are taking research and action into their own hands, often partnering and collaborating with outside experts, to address the pollution and disease disparities confronting their communities.

I highlight the work of two G/W community-based organizations, El Puente and The Watchperson Project. Through in-depth interviews, reviewing primary texts, and ethnographic fieldwork, I describe the processes each organization has used to investigate and act upon two local health issues: asthma and subsistence fishing. El Puente is a community organization with a long history of social justice organizing among the Latino residents of Williamsburg. I describe their health survey research around asthma, which is aimed at addressing the causes, triggers, and management of the disease (12). El Puente, partnering with the nonprofit organization Community Information and Epidemiological Technologies (CIET), has emphasized local ownership over the research process and the results, all geared toward collective self-help (12). Although some of the results of El Puente's work have already been published (12,13), I emphasize the processes they have used in their research, paying particular attention to how they have gathered and used community knowledge to understand and act upon the elevated rates of asthma in the Latino community. In a second case I review the work of The Watchperson Project, a neighborhood watchdog, research, and advocacy organization. I describe how the group partnered with the U.S. Environmental Protection Agency (U.S.

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EPA) to research local subsistence-fishing practices, and how the community group's research contributed key data inputs into the U.S. EPA first community-based cumulative exposure project (CEP). I review the community-based research process, paying particular attention to how local knowledge was incorporated into the U.S. EPA risk assessment, and report on the assessment findings. Through both examples, I suggest how communities living with environmental health hazards and chronic disease can contribute local knowledge and expertise, often overlooked or unattainable by outside researchers, that can contribute to both locally relevant health interventions and to extending the work of professional scientists.

### Neighborhood Exposure Profile

The G/W neighborhood, defined by Community Board Number One in Brooklyn, has approximately 160,000 residents living in an area of less than 5 square miles. These residents are some of the poorest in New York City, with 35.7% of the G/W population living below the poverty line (14). The median household income for the neighborhood is \$16,409 compared with \$25,684 for Brooklyn, and \$29,805 for New York City generally (14). In addition to the poverty issue, only 43.7% of adults over 24 years of age have a high school diploma or higher level of education compared with averages of 63.7% in Brooklyn and 68.3% in New York City generally (15). The ethnically diverse neighborhood is approximately 42% Latino (mostly Puerto Rican and Dominican), 24% Hasidic Jew, 13% African American, and 10% Polish and Slavic immigrants (14).

The neighborhood has the largest amount of land (12%) devoted to industrial uses than any of New York City's 59 community districts (15). The average percentage of industrial land use for all districts in the city is 1.9% (15). The neighborhood houses a disproportionate number of polluting facilities in New York City, including the Newtown Creek sewage treatment plant; 30 solid waste transfer stations where garbage is stored before being transported to landfill; a radioactive waste storage facility; 30 facilities that store extremely hazardous wastes, 17 petroleum and natural gas storage facilities; and 96 above-ground oil storage tanks (16). In 1987 a study by the Hunter College Community Environmental Health Center called "Right-to-Breathe, Right-to-Know" revealed that Williamsburg was home to the largest concentration of industries reporting to the U.S. EPA Toxic Release Inventory (TRI), many of which were not in compliance (17). Not much had changed 10 years

later. In 1997 the community housed 60 facilities storing, using, or manufacturing 10,000 pounds or more of a hazardous substance, 161 facilities reporting hazardous substances in the citywide facility inventory database, 21 TRI facilities, and 11 facilities using or storing extremely hazardous materials with risk management plans (16). These numbers rank the neighborhood first out of all community districts in New York City for housing the highest number of these facilities. Residents are also exposed to heavy vehicular traffic and mobile source pollution from the Brooklyn–Queens Expressway, an elevated roadway that bisects the community. Finally, only 3.0% of the neighborhood is shaded by trees, compared with an average of 11.4% tree cover for all Brooklyn neighborhoods and an average coverage of 16.6% for all of New York City's neighborhoods (15).

Despite the plethora of environmental hazards in the G/W neighborhood, few attempts have been made to understand and document neighborhood residents' health. The New York City Department of Environmental Protection (DEP) supported two neighborhood health studies of G/W, focusing on rates of cancer, asthma, birth defects, and childhood lead poisoning. These studies found that the incidence of stomach cancer, certain types of leukemia in men, pancreatic cancer in women, cancers of the central nervous system, and certain leukemias in children were among the highest in New York City (18,19). Another study by the DEP attempted to capture the cumulative environmental load for each census block group in the G/W neighborhood, called the baseline aggregate environmental loading (BAEL) profile (20). The BAEL project was never finalized, but draft reports gathered data on land use, demographics, the location of toxic releases, some health end points, and the location and number of residents' air and odor complaints in the neighborhood (20). With a paucity of environmental health research being conducted in regulatory agencies, some neighborhood organizations decided to conduct their own community health research.

### El Puente: Asthma Research and Action

In an effort to better understand and improve the health of the community, El Puente, a community learning and development institution located in Williamsburg's Southside, conducted a series of community health surveys between 1995 and 2000 focusing primarily on asthma (12). Designed, administered, and interpreted by community residents with the assistance of CIET, the surveys have enabled El Puente to

learn about neighborhood health, the challenges residents face in maintaining their health, and how to structure health interventions that resonate with and make sense in people's daily lives. The asthma research and action is one part of the organization's environmental health and justice program, which includes issues ranging from stopping neighborhood waste-transfer stations to creating community gardens (21). This section reviews some of the methods El Puente used in the CBPR process, paying particular attention to how residents' local knowledge was revealed and how this knowledge contributed to community-based health-promoting activities.

El Puente's health survey research "stems from the conviction that science should be used as an instrument for collective self-help" (21). The group's work was partly stimulated by students in the El Puente Academy for Peace and Social Justice, a public magnet high school housed in and run by the community organization, who were concerned with neighborhood air pollution and alarming rates of asthma (21). The academy had been a focal point for community health organizing since 1988, when science class students organized the "Toxic Avengers," a group of teenagers committed to education and organizing in order to take action against a poorly performing radioactive waste storage and transfer facility in the neighborhood (22). When science students again expressed an interest in air pollution and health issues in 1995, El Puente enrolled CIET to help students survey the student body, family, friends, and neighbors about their perceptions concerning local environmental and health issues (23). CIET helped train students and some residents in survey design and administration along with the etiology of asthma. The students participating in the survey eventually organized the Williamsburg Environmental Preservation Activists and acted as the first team of community residents to perform El Puente's door-to-door health survey (24). With financial assistance from the Nathan Cummings Foundation, 50 El Puente Academy high school students, five teachers, and five El Puente staff members interviewed residents door-to-door, reaching 280 households and 1,065 individuals (25). This first survey revealed to El Puente that residents felt there were serious problems of air pollution and respiratory disease in the neighborhood; however, most residents had not taken nor were they aware of any actions they could take to address these conditions (25). Although preliminary, the findings provided the impetus to plan a series of community health surveys and related action to combat asthma (23).

## Research Philosophy

El Puente and CIET adopted a research methodology called sentinel community surveys or service delivery surveys (26). With these methods a mix of quantitative and qualitative data is gathered by existing community organizations trained to conduct questionnaires, face-to-face interviews, and public discussions of survey design and results—all with the intention of collective action (26). The research philosophy is rooted in the Latin American tradition of participatory action research, which emphasizes that research should be understood as a process of education, and pedagogy as a practice of social transformation (27–29). El Puente used a form of listening research, a technique emerging from rural appraisal in which teams of community residents, trained by research scientists, employ their own skills in observation, questioning, semistructured interviewing, and group discussions to gather data (30). Fundamentally, the key components of El Puente's research approach include: *a*) community ownership of both the information and the research process; *b*) the premise that research will lead to action for the benefit of the community; and *c*) the weaving of research into a process of community reflection and learning (12,30).

## Community Health Educators

After the 1995 survey, which was performed mostly with high school students and volunteers, El Puente decided to employ a dedicated survey staff from the neighborhood to obtain more detailed information and to develop a sustained health research effort (31). Following in the research traditions of participatory action research, El Puente recruited community members to act as health promoters to administer the surveys, lead community discussions about interpretations of results, and help residents generally manage their asthma and health (32). According to Cecilia Iglesias-Garden, coordinator of El Puente's health workers, the objective was to hire community health workers from the community who had long-term ties, commitment, and knowledge of the neighborhood, including people who knew about available neighborhood social services (32). According to Iglesias-Garden, it was also important for the organization to recruit community members with a personal or familial association with asthma, those who had experience dealing with the daily challenges of living with asthma, and residents who had a passion for improving the health of the community (32). Eventually, El Puente chose 10 Latinas from the community, all Puerto Ricans and Dominicans, to be a part of their community health educators (CHE) team.

The CHE women and CIET scientists worked together to develop the asthma survey program: the technicians educated the women in the science of asthma and survey design, and the residents educated the scientists in local culture, language, and common health practices. The women became the centerpiece of El Puente's community health worker model. In this model, community health workers are lay health advocates and advisors who learn from and help educate individuals and groups toward increased well-being (33–35). The workers act as bridge builders between residents, cultural and folk practices, and professional providers of clinical healthcare (33). This can be accomplished when the women workers offer basic disease education, screening, and detection techniques; translate the cultural and folk practices for unknowing healthcare providers; and seek out professional healthcare for those who desire it (34). In New York City's Latino communities, the community health worker tradition dates to the Young Lords, "barefoot doctors" of the 1960s, who worked to raise public consciousness of lead poisoning in East Harlem (35). Community health worker models are also increasingly used in research to help investigators understand and treat asthma in urban settings (36–38).

With the CHE in place, El Puente performed a second survey reaching 727 households and 2,311 individuals (31). The increased response rate was attributed to the presurvey organizing of the CHE and the ability of the CHE, when at the door, to respond credibly to the urgent health needs they encountered. According to Iglesias-Garden, although it was important that the health workers could speak credibly about asthma:

The first thing most people asked us had nothing to do with asthma, but rather about another medical problem they had or where they should send their kids for school or where to get free food to feed their family that evening. (32)

The credibility of community researchers with other residents, which often includes having an intimate knowledge of a place, has been noted as one of the key factors for successful CBPR (39). The credibility of the CHE team also contributed to widespread community participation in focus group discussions that followed each survey.

## Focus Groups and Local Knowledge

The community research enabled El Puente to establish, for the first time, a peer-reviewed asthma rate for the Latino community in Williamsburg. El Puente calculated an 8.5% active asthma rate generally and a

12.4% active asthma rate for children, both more than twice the national rate of 5.4% (13). These rates were based on the period prevalence, or the percentage of the survey population told by a doctor they had asthma and who had experienced one or more asthma symptoms in the previous 12 months. Other survey findings revealed that residents who had been living the longest in the neighborhood had the highest prevalence of asthma; over half the respondents did not have health insurance; many new immigrants avoided professional healthcare; and residents who came directly from Latin American or the Caribbean had half the risk of having been diagnosed with asthma than those who came from other areas within the United States (13). Although these and other findings helped El Puente begin to take action against asthma, such as enrolling residents in a free New York State healthcare program, it was during a series of community focus group dialogues that stories emerged about why some of these phenomena might be occurring.

The focus groups were informal community meetings where the young and old, asthma sufferers and those without the disease, gathered to discuss interesting, surprising, or incomplete findings from the door-to-door interviews. The meetings often provided contextual meaning and narratives behind the survey numbers. For example, one survey found that women over 45 years of age had a high prevalence of asthma similar to that found in children. This was surprising, as children, not older women, are generally suspected as the group most vulnerable to developing asthma. During focus group discussions, El Puente heard from women that they typically worked in laundries, dry cleaners, hair and nail salons, and textile factories—all occupations with potentially hazardous exposures that could exacerbate respiratory disease (21). Although the group is working to identify more exact explanations for the high rate of asthma in older women, it is unlikely they would have considered workplace exposures as a potential cause without the focus group dialogues.

The survey also revealed that many residents relied on herbal and other culturally derived home remedies to treat asthma, sometimes in place of physician-prescribed medication (13). Examples of common remedies used to treat asthma included mixtures of aloe, honey, and lemon; radish, onion, honey, and shark oil; and snake oil mixed with various herbs (40). However, the survey was not able to specify why the home remedies might be substituted for pharmaceutical medication (32). According to Robert Ledogar, an epidemiologist with CIET, one concern was that home remedies

might be toxic or exacerbating asthma attacks; an equally important concern was to understand the different cultural and spiritual aspects of home remedy use and how these differed among neighborhood Latinos. The use of herbs and home remedies is widespread in Latino cultures, especially for those following the spiritual practices of Santería and Espiritismo, popular among Caribbean Latinos from Puerto Rico, the Dominican Republic, and Cuba (41). The focus groups provided an opportunity to identify more precisely the home and herbal practices that Latinos were using, the spiritual and cultural ties associated with the use of home remedies, and why they might be substituted for physician-prescribed medication.

The focus group discussions about home remedies brought youth and elders together, along with local practitioners of herbal medicine from Puerto Rico, the Dominican Republic, Ecuador, and other Central American countries. Importantly, the focus group process allowed those often marginalized in community health, particularly folk healers, to become valued participants in the research process. The CHE women facilitated the discussions of the home remedies. According to Iglesias-Garden of El Puente, the women made a conscious effort during the focus group process not to allow other community members or outside researchers listening in to judge the home remedies; instead they worked to help participants develop a keen understanding of the practices as well as respect for their cultural and spiritual origins. When the discussion turned to why some residents were substituting home remedies for prescribed asthma medications and not informing their physicians, most residents told of being shunned and ridiculed by their healthcare provider when they tried to explain their cultural or spiritual practices (32). Many residents stated that they had a hard time trusting a physician who did not understand, appreciate, or take seriously their spiritual and traditional practices (21). As a result, some residents did not trust the prescribed medication and others did not visit a physician at all, preferring their time-honored traditional practices.

Focus group dialogues also helped reveal why Dominicans were more than twice as likely to use home remedies than Puerto Ricans (13.2 vs 5.3%, respectively), another survey finding (13). Dominicans who had more recently arrived in the neighborhood spoke of being more disassociated from the healthcare system than, for instance, their Puerto Rican neighbors. According to Ana Migdalia Flores, a member of the CHE team and focus group discussion facilitator, Dominicans often stated that home remedies “helped them connect with others who could

help them integrate into the community,” suggesting to her and El Puente that home remedies not only represented medicinal practices but also helped keep new immigrants connected to their social networks. The importance of community networks for promoting health has been noted in Mexican American children who, despite having higher levels of poverty, lower levels of parental education, and more limited access to healthcare than non-Latino White children, have unexpectedly low rates of adverse perinatal results and prevalence of chronic and disabling conditions (42). The focus groups helped provide important contextual narratives to the quantitative survey data and revealed that, for many Latinos, maintaining health was inseparable from the daily rhythms of everyday life.

### Knowledge for Action

Ultimately, all of El Puente’s research was directed toward taking proactive steps to improve the living conditions and health of Southside residents. El Puente learned from community expertise what types of interventions were most urgently needed and which would most appropriately resonate with residents’ daily lives. With the support of the New York City Department of Health Childhood Asthma Initiative, the CHE women began an asthma mastery program to enable them to train community members in developing individual and family asthma management plans. Students continue to be integral partners in the asthma research by participating in interviewing and focus groups, painting community murals depicting the effects of asthma and what to do about it, and producing an asthma awareness public service announcement for local cable television (21). The CHE have initiated a cultural competency program to train local healthcare providers in Latino folk medicinal practices (32). After learning that most residents were uninsured despite the availability of free health coverage from New York State, El Puente organized residents to enroll in the free insurance program. The National Institute of Environmental Health Sciences (NIEHS) has also recognized the

value of El Puente’s work. NIEHS recently funded the group to continue its research and act as the principal investigator for an expanded 4-year asthma study, which will include physicians from Woodhull Medical and Mental Health Center and the Department of Environmental Medicine of the New York University School of Medicine (43). El Puente’s work appears to be paying off; not only have they educated and enrolled hundreds of community members in their asthma mastery program, but asthma hospitalizations in their community district have decreased from 1,166 in 1997 to 484 in 1999 (44).

### The Watchperson Project: Cumulative Exposures and Subsistence Fishing

A second CBPR process in the G/W neighborhood highlights not only how the process can mobilize residents to take action, but how community research can also contribute to and extend the work of conventional scientific practice. In this case, The Watchperson Project and the U.S. EPA partnered to develop the U.S. EPA first community CEP. The CEP was an attempt by the U.S. EPA to move beyond the single-source, single-hazard approach to assessing risks and instead to recognize from the outset that some populations, specifically the poor and people of color, are simultaneously exposed to multiple environmental pollutants from multiple sources (45).

Cumulative assessments are intended to differ from the traditional single-source risk assessment approach on a number of fronts (Table 1). First, cumulative assessments consider multiple pathways, sources, and end points, whereas conventional risk assessments consider only a single pathway, source, and end point (46). For example, exposure assessment focuses on populations, not individuals, and aggregates by population subgroups, such as those highly exposed and highly sensitive. Highly exposed populations can be further aggregated by specific geographic area (i.e., neighborhoods), age, gender, race, ethnicity, and economic status. Highly sensitive populations are also further divided by categories such as those with preexisting conditions (i.e., asthmatics), age (i.e., infants), and

**Table 1.** Risk assessment versus cumulative exposure assessment.

Traditional risk assessment	Cumulative exposure assessment
Single exposure pathway	Ingestion, inhalation, dermal, and indirect
Single source	Multiple sources
Single end point (carcinogenesis)	Exposures not single disease
One linear dose (mostly high acute)	Varied dosage (includes low chronic)
Modeling (dependent on rodent studies)	Epidemiologic and no-observed-effects considered
Maximally exposed individual	Actual measured exposures
Probability outcome—point or Monte Carlo	Characterization by toxicity and health end points
One-size-fits-all, single stressor	Case specific, holistic
Expert-dominated, centralized assessment	Community-based decision making

Data from U.S. EPA (46).



gender (i.e., pregnant women) (47). Cumulative assessments recognize multiple pathways, such as ingestion, inhalation, and dermal contact, while also exploring potential routes of population exposure, such as direct or indirect contact, bioaccumulation, biomagnification, and vector transfers (i.e., mosquito bites) (47). A cumulative assessment also considers a multiplicity of human health end points, such as carcinogenic, neurotoxicologic, reproductive, developmental, immunologic, renal, and hepatic (46). Cumulative exposure assessment also considers the different frequencies, durations, and intensities of exposures, such as chronic low doses where there might not be any observable adverse effect (46). Finally, the U.S. EPA has recognized that because some of the necessary information for community-specific assessments cannot be modeled solely in a laboratory, the cumulative assessment process departs from a one-size-fits-all centralized model of decision making and embraces a case-specific, community-based decision-making model (46,47).

The CEP in the G/W neighborhood examined how much toxic contamination residents are exposed to through air, food, and drinking water. The study modeled the local dispersion of 148 hazardous air pollutants and added hazardous food and water ingestion exposures to derive a cumulative community exposure profile (48). Here I review only the assessment of hazards from subsistence-fishing diets and the role that CBPR played in this data gathering and assessment process.

### Tapping the Local Knowledge of Subsistence Anglers

According to project manager Fred Talcott, the U.S. EPA chose the G/W neighborhood for its first CEP for at least three reasons: *a*) the U.S. EPA suspected there were significant exposures in the neighborhood; *b*) the neighborhood had an organized set of community organizations working on environmental health issues; and *c*) the New York City DEP had gathered some preliminary pollution data in the area and developed a program—the Environmental Benefits Program—specifically targeting the neighborhood (49). This program was an outgrowth of community organizing and a lawsuit challenging discharges at a DEP sewage treatment plant in the G/W neighborhood, and it was through this program that The Watchperson Project was created (16–20). Initially, the CEP consisted of U.S. EPA experts trying to integrate a series of New York City DEP and U.S. EPA data into an established modeling methodology, with little consultation with community organizations (48). However, during a series

of community meetings about the CEP, the agency heard from community residents that their methods were missing some potentially hazardous exposure information. According to Samara Swanston, director of The Watchperson Project, the U.S. EPA methods for the dietary assessment seemed inadequate to most residents because they were based on a series of default “urban diet” assumptions, which lacked any specific information on the diets of the diverse ethnic populations and also ignored the potentially hazardous exposures from eating locally caught fish (50). Residents suggested during the community meetings that a large number of local people were subsisting on a diet of East River fish. This was the first time the U.S. EPA had heard of this potential health hazard, and neither the U.S. EPA nor the community had any detailed data about subsistence fishing beyond anecdotal evidence (49).

The Watchperson Project emphasized to the U.S. EPA that not only were the hazards from subsistence fishing a potentially significant dietary exposure, but also that because many of the anglers were immigrants and non-English speakers, they would likely be reluctant to speak with outside researchers about their practices (50). The community group suggested that if there were to be an effort to capture angler exposure data, local people would likely be the only ones trusted by the anglers to share information about their fish diets (50). After considering ignoring the subsistence-fishing exposures or having community members gather this information, the U.S. EPA agreed to help The Watchperson Project collect information about the practices of local anglers. According to Talcott of the U.S. EPA:

After we learned from residents that they were eating fish from the East River, we had no choice but to let the community groups gather the data. For a number of reasons, including language, cultural barriers and potential trust issues, we felt the local people could best gather this data. This was one situation where residents raised an issue we hadn't considered, defined the extent of the problem, and provided the data for analysis. (49)

The Watchperson Project worked with the U.S. EPA to develop a protocol to interview anglers and to identify the approximate number of people eating fish from the river, the amounts and frequency of fish consumption, and the types of fish anglers and their families were eating. U.S. EPA scientists offered the community group survey instruments used to capture similar information in other communities, and The Watchperson Project tailored these surveys into one appropriate for the local population (50,51). The community group spent 3 months interviewing anglers at the India Street and the

North Seventh Street/Kent Street Piers along the East River (48). Community members volunteering with The Watchperson Project visited the piers twice a day for 2 weeks during August and September and observed and interviewed over 200 anglers. Each angler was asked about their age, race, country of origin; the number and age of people in their family; and species of fish and number regularly caught and eaten. Because the interviewing was conducted during the summer, each interview included questions about seasonal variability and frequency of catches in different seasons. Finally, each angler was asked about their fish consumption patterns and those of their family, including the species, quantities, and preparation techniques of the fish they ate (48).

### Angler Survey Findings

The information gathered by the community was divided by age and ethnicity, and separate categories were created for Whites, Poles, African Americans, and Latinos (48). Almost all the anglers interviewed were Latino or African American, although some were Caucasian (primarily Slavic). Of the Latinos, most had origins in Puerto Rico, the Dominican Republic, or Ecuador (48,50). The Watchperson Project also found that almost all the anglers were males between 16 and 60 years of age. The family size of each angler ranged from 3 to 10 persons, and all anglers interviewed noted that at least one family member was under the age of 19 (48). The Watchperson Project survey determined that local anglers were catching between 40 and 75 fish per week, averaging 57 fish per week, and that each family member of an angler was eating approximately 9.5 fish per week (48). According to one angler,

Look, this is my way of feeding my family. I ain't got no job and this is what I did in the D.R. [Dominican Republic]. I got to feed 5 or 6 people a night. Know what I mean? (52)

Each angler was also asked to identify the four species they most frequently caught and consumed. All the anglers interviewed listed the same four species: blue crab, American eel, bluefish, and striped bass (48). Most anglers reported they ate whatever they caught. One of the challenges for the interviewers was that anglers might not have been accurately identifying the fish they caught and ate (50). Therefore, the interviewers also collected fish samples to confirm species identification.

U.S. EPA analysts performed toxicologic tests on fish from the East River and compared these data with fish contaminant estimations from previous studies performed by the New York State Department

of Environmental Conservation (48,53,54). From these data, the U.S. EPA determined that the contaminants of concern in the locally caught fish included cadmium, mercury, chlordane, DDT, dieldrin, dioxins, polychlorinated biphenyls, arsenic, and lead (48). However, arsenic was removed from the analysis because, according to the U.S. EPA,

much of the arsenic in edible fish is present as arsenic-containing organic compounds . . . and these organic forms of arsenic are generally not considered a threat to human health. (48)

In addition, because lead exposures were going to be analyzed in a separate multimedia study under the CEP, lead was also removed from the fish contaminant analysis (48,49).

Using the community survey data, the U.S. EPA generated a consumption rate for G/W residents in grams per day, which was consistent with U.S. EPA data from other communities relying on subsistence fishing (48,55). Resident exposures were then calculated on the basis of fish tissue contaminant concentrations found in actual samples and the consumption rates. High- and low-end consumption rates for both adults and children were calculated to develop a range of exposure estimates (48). The estimated exposure levels for G/W anglers and their families exceeded U.S. EPA oral reference doses (which generally serve as benchmark levels for noncancer health effects) for all contaminants except cadmium at both low- and high-end consumption estimates (48). Exposures to dioxins were particularly high. For example, the U.S. EPA reference dose for dioxin is  $1 \times 10^{-9}$  mg/kg/day, whereas the estimated exposure level for the average high-end adult eating locally caught fish in the G/W neighborhood is  $8.2 \times 10^{-8}$  mg/kg/day, and for the average high-end child fish consumer the estimated exposure level is  $1.5 \times 10^{-7}$  mg/kg/day (48).

Finally, the U.S. EPA calculated a lifetime cancer risk for adult subsistence anglers in the G/W neighborhood and found that the risk exceeded 1 in 10,000 ( $1 \times 10^{-4}$ ) for every exposure scenario. This is significant because an acceptable cancer risk for the U.S. EPA is one in a million ( $1 \times 10^{-6}$ ). For subsistence anglers at the high-end consumption rate, the estimated individual lifetime cancer risk across all contaminants ranged from  $8.7 \times 10^{-2}$  for the single-species maximum contaminant concentration to  $5.8 \times 10^{-3}$  for the minimum contaminant concentration. Using the cross-species average contaminant concentration, consumer across species, the estimated individual lifetime cancer risk for the high-end fish consumer was  $4.2 \times 10^{-2}$  and  $6.0 \times 10^{-3}$  for the low-end fish consumer

(48). Without the community-generated information, the U.S. EPA would likely have ignored this potentially serious health hazard. In the final analysis the U.S. EPA arrayed the results of each individual exposure assessment to show the range of contaminant exposures that exceeded health benchmark levels (48).

### Taking Action

Whereas the U.S. EPA spent more than 5 years completing the CEP in the G/W neighborhood, The Watchperson Project could not wait that long to take precautionary and preventative action. As their survey interview data began to suggest just how many residents were eating fish from the river, The Watchperson Project organized a series of “fish-in” days to educate anglers about potential toxic contamination in the fish they were eating and to clean up the riverbank. The community group developed educational materials, printed in English and Spanish, describing possible health risks from eating locally caught fish and suggested such things as cleaning and cooking techniques that might reduce contaminant intake. Because the community group was aware that most anglers were driven to subsistence-fish diets out of poverty and cultural tradition, “telling anglers to just stop eating these fish, while maybe the safest thing, wasn’t a reality for many of them” (50). The Watchperson Project has been working with other community organizations in the area to identify alternative sources of food for subsistence anglers, such as community gardens. Finally, the community organization was asked by the New York State Department of Environmental Conservation to share their survey findings to assist the agency in developing culturally sensitive practices for enforcing existing fish advisories along the East River (50).

### Discussion

The two CBPR processes in the G/W neighborhood suggest that community knowledge is essential for understanding environmental hazards and for developing contextually relevant interventions to eliminate the hazards in communities experiencing environmental injustice. Together, the two processes offer lessons in how CBPR can most effectively contribute to reducing health disparities facing the poor and people of color. First, each process stressed that a lack of data should not lead to an assumption of an absence of hazard. Too often, disease and environmental exposure information do not exist for the poor and communities of color, and this ignorance leads researchers and agency decision makers to assign zero risk where little or nothing is known. Community research is

crucial for filling the voids and gaps in health department and environmental regulatory agency databases (3). However, the burden should not fall to community organizations alone to fill gaps in existing data that agencies and other researchers should be collecting.

A second lesson is that community members, regardless of their level of formal education or fluency in English, can be equally expert as conventional scientists in gathering information about hazards and disease in their own communities. In the G/W neighborhood, community members were the only experts who could gather information on such things as angler practices and the home remedies used by Latinos to treat asthma. For CBPR to address environmental injustices, it must recognize that local people have a privileged form of knowledge and expertise about the places where they live—much like one has an intimate understanding about certain aspects of one’s own body. This suggests that the word “expert” should not be conceptualized in binary terms such as expert–lay but rather as a fluid and heterogeneous concept where, depending on the question asked, scientists and community members can be equally expert. By explicitly recognizing community expertise, CBPR holds the potential for environmental justice communities to speak back to the often hegemonic power of scientific expertise to define, analyze, and dictate solutions for those most at risk.

A third lesson for CBPR is that community should be understood as both a geographic place and an identity group. El Puente recognized that they could not be effective administering a survey within the entire political boundaries of the G/W neighborhood and instead focused on the Latino community where their organization was based. Common symbols, language, heritage, norms, and life experiences can define community as much or more than geography, and successful CBPR for environmental justice must make this explicit in the research process. The sharing of personal histories and narratives with others from similar heritage turned out to be more important than geography for capturing the meanings people attached to their experiences, such as why residents preferred home remedies or were driven to eat fish from the East River.

Another lesson from the CBPR processes is that to identify community, researchers should look to organizations already established in the community (39). Part of the success of the CBPR in the G/W neighborhood was that each project did not try to create new institutions or organizations but built out from established groups that had the trust and credibility of local residents. El Puente started their survey with committed

high school students and furthered the process by organizing existing residents committed to battling asthma. El Puente also employed local women as a part of their CHE team, all of whom were residents with strong neighborhood and cultural ties. The Watchperson Project recruited trusted and recognized residents who could culturally relate to the anglers and speak their language.

A fifth lesson for CBPR is that community residents should be seen as full partners in all aspects of the research process. In El Puente's research, residents were involved in all aspects of survey design, administration, and analysis. When residents are full partners in the research process, they are more likely to retain ownership and trust in the process and results. Issues of research transparency, trust, ownership, and self-determination continue to concern communities, especially the poor and people of color who have either been ignored by researchers or, when asked to participate as subjects, are often abandoned in the end by researchers intent on analyzing results only for their own advancement and not for community improvement. Local ownership ensures that community knowledge garnered through research is used to educate others in the community and promote well-being. The CBPR in the G/W neighborhood also revealed that social learning about environmental health issues can occur among community residents, debunking the notion that communities always have a deficit of important health knowledge and require education from outside experts in order to act appropriately.

Local ownership also contributes to locally generated action, perhaps one of the most fundamental aspects of CBPR (39). For environmental justice advocates, CBPR must be action oriented, where contingent interventions are developed before results are finalized, with the understanding that community action can be fallible. El Puente demonstrated this as they enrolled uninsured children in New York's free healthcare program and recruited asthma sufferers to develop asthma management plans before the organization completed their survey analyses. By encouraging precautionary and preventative action, CBPR holds the prospect of challenging research that has contributed to inaction over the disparate environmental and health burdens afflicting the poor and people of color.

To take action before results are complete and to learn from these experiences, successful CBPR for environmental justice must also be long-term and iterative, not a "one-shot deal" (3). El Puente has been working on their surveys since 1995, learning from the successes and failures of each to

reach more households, ask more specific questions, and structure more informative focus group discussions. Although The Watchperson Project's survey was more of a one-time effort, they too have drawn from the experience to develop a long-term commitment to educating and advocating for local anglers. The long-term and iterative nature of the process recognizes that the assessment of environmental health issues has a temporal dimension often poorly recognized by conventional science. As local pollution concentrations, resources, and health conditions change, so too will the necessary actions to promote environmental justice. CBPR is situated to capture how new circumstances, understandings, and identities might allow for a continual community reassessment of the proper thing to do to address ever-changing circumstances.

Finally, the CBPR in the G/W neighborhood revealed that the process can contribute not only to local action for improving the lives of community members, but it can also extend the work of conventional science. The angler data gathered by The Watchperson Project greatly expanded the dietary aspect of the U.S. EPA CEP. The work of El Puente has revealed the importance of local knowledge for understanding such things as culturally rooted medicinal practices to address asthma. Publication of El Puente's findings in peer-reviewed journals and the acknowledgment of their work by the NIEHS both suggest that conventional science is recognizing the value of their work. While the knowledge revealed through CBPR can contribute to existing scientific understandings, it also attempts to change the questions, redefine problems, and increase the social relevance of conventional science. The local knowledge of community residents that CBPR taps into can improve the interventions of public health professionals by making the actions relevant to lived experience, and both cases here highlight how this is especially important in ethnic and immigrant communities. Ultimately, although CBPR can contribute to and extend the work of conventional science, the environmental justice movement recognizes that research alone may be inadequate to address the political, economic, and social decision-making processes that contribute to disproportionate environmental health burdens for the poor and people of color.

## Conclusions

In the pursuit of environmental justice, communities of color recognize that they must begin to frame research agendas from the outset, help define problems, and engage with scientists in data gathering and analysis

if the research is to accurately address the hazards and health problems they face. Conventional science can offer a great deal to communities that persistently bear the burden of society's hazards. Thus, research and action partnerships between communities and scientists are increasingly essential for understanding and reversing environmental injustices.

The CBPR processes in the G/W neighborhood revealed that local knowledge can identify gaps in expert assumptions, improve professional understanding of local practices, and identify locally relevant health-promoting interventions. The processes also revealed that community residents can be "citizen scientists," working with conventional scientists, not in place of them. Community knowledge helped reveal the limits of expert assessments (such as when residents highlighted that the U.S. EPA missed exposures for subsistence anglers), and if given the opportunity, can also extend scientific understandings. As local residents, their knowledge and experiences are meaningfully incorporated into research processes, and when these same populations have a chance to develop appropriate interventions, CBPR can contribute to the pursuit of environmental justice.

CBPR is not without its limits and challenges, such as addressing the structural issues that may be contributing to inequitable distributions of disease and environmental hazards. By focusing on immediate health and environmental gains, CBPR can sometimes ignore the economic, social, and political factors that often determine which populations have resources to resist hazards and promote health. Additionally, I am not suggesting that CBPR be romanticized as a panacea for ensuring that environmental health research addresses the inequities facing the poor and people of color. However, as CBPR must often operate with substantially less financial support than conventional methods and under a constant cloud of institutional skepticism, it is difficult to assess CBPR's full potential and limitations.

As communities of the poor and people of color continue to demand to speak for themselves, CBPR remains one important process toward environmental health justice. Research alone will not address existing inequalities. Political organizing and greater democratic participation in environmental health decision making must also accompany the prospective research paradigm shift offered by CBPR. Further articulating the benefits and challenges of this alternative research approach is our imperative, for the well-being of disadvantaged communities may hang in the balance.

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